

Comparison of Engagement in Care Measures using Self-Report and Clinical Records Data

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Overview of HIV in Washington, DC

- One of highest HIV/AIDS prevalence in U.S.
 - 15,056 people (2.4%)
- 4,919 newly diagnosed HIV cases between 2007-2011
- Persistent gaps in the continuum of care
 - Retention
 - Suppression



HIV Continuum of Care among Newly Diagnosed Cases, 2007-2011 through 2012



Source: Adapted from DC Dept. of Health, 2013 Annual Epidemiology and Surveillance Report

DC DOH Recapture Blitz

- Objective: To identify persons previously in care who have fallen out of care and re-engage them into care
- Methods
 - Clinics send lists of out of care patients that are matched to DOH surveillance and services data to determine whether dead, receiving care elsewhere or truly out of care
 - Clinics receive updated list and contact patients to re-engage them
- Recapture Blitz (2013) finds and re-engages clients lost to care



Objectives

- Study Objectives
 - To identify predictors of retention in HIV care through linkage of clinic-based and surveillance data, and patient-level surveys.
 - To identify individual and structural-level barriers and facilitators to engagement and retention in HIV care through the conduct of qualitative interviews with patients and providers.
- Analysis Objectives
 - To assess for differences in care-status measures collected from patient self-report and clinical records data



Methods

- Survey Methods
 - Conducted interviewer-administered surveys to patients receiving care at 3 clinic sites
 - Participants provided self-reported visit frequency and recruited based on care status
 - Participants assigned HRSA stage of care status
 - In-care (IC), Sporadic care (SC), Out of care (OOC)
- Analytic Methods
 - Linked self-reported and clinic-level data
 - Compared varying care stages using uni and bi-variate analyses
 - Compared agreement between care status using Kappa statistic and ROC curves



Recruitment of In Care/Sporadic Care Participants





Recruitment of Out of Care Study Participants





Results: Survey Participant Demographics (N=164)

| Demographics | Percentage | | |
|---------------------------|--|--|--|
| Age (years) | Median 51 (Range: 21-72) | | |
| Sex (male) | 65.1 | | |
| Race (black non-Hispanic) | 68.7 | | |
| Insured in past 12 months | 92.6 | | |
| Homeless/unstably housed | 23.8 | | |
| Education (HS or less) | 49.4 | | |
| Unemployed | 60.7 | | |
| Co-morbidities | | | |
| Mental Health | 47.6 | | |
| Hepatitis C | 29.3 | | |
| Cardiovascular disease | 28.7 | | |
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Results: HIV Care Patterns by Group (N=164)

| Care Patterns | IC (n=116) | SC (n=33) | OOC (n=15) | P-value |
|--|--------------|---------------|--------------|---------|
| | % | % | % | |
| Time since HIV diagnosis (yrs) | Median: 16.2 | Median: 14. 1 | Median: 18.8 | 0.2460 |
| Linked to HIV care ≤ 3 mo. | 69.8 | 78.8 | 73.3 | 0.5952 |
| Longest period without HIV medical care | | | 1410 | 0.0209 |
| < 6 months | 57.8 | 39.4 | 26.7 | |
| 6-12 months | 12.9 | 33.3 | 26.7 | |
| >12 months | 29.3 | 27.3 | 46.7 | |
| Seen provider for any non-HIV related visits in past 12 months | 80.2 | 75.8 | 73.3 | 0.7493 |
| Ever on ARVs | 95.7 | 87.9 | 100.0 | 0.1398 |
| Currently on ARVs | 99.1 | 93.1 | 86.7 | 0.0183 |
| ARV adherence past 7 days (all pills) | 82.6 | 65.4 | 69.2 | 0.2836 |
| 9th International Conference on | | | | 8333 |

Self-Reported Status along Care Continuum: In Care Group

| Not in Care | | | | Fully Engaged |
|---|--|---|---|---|
| Aware of HIV status (not in care) | Receiving some medical care but not HIV care | Use HIV care intermittently, that is every once in awhile when needed | Entered into HIV care but never went back | Fully engaged in HIV primary care |
| 0 | 2 | 4 | 0 | 97 |

* Unknown: n=13

IC



Self-Reported Status along Care Continuum: Sporadic Care Group

| | Not in Care | 1 | | | Fully Engaged |
|----|---|--|---|---|--------------------------------------|
| | Aware of HIV status (not in care) | Receiving some medical care but not HIV care | Use HIV care intermittently, that is every once in awhile when needed | Entered into HIV care but never went back | Fully engaged in HIV primary care |
| C | | | | | |
| SC | 0 | 0 | 1 | 0 | 20 |

* Unknown: n=12



Self-Reported Status along Care Continuum: Out of Care Group

| Not in Care 🧳 | | | | Fully Engaged |
|---|--|---|---|--------------------------------------|
| Aware of HIV status (not in care) | Receiving some medical care but not HIV care | Use HIV care intermittently, that is every once in awhile when needed | Entered into HIV care but never went back | Fully engaged in HIV primary care |
| | | | | |
| 0 | | 1 | 0 | 20 |
| 0 | 0 | 6 | 0 | 9 |



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Results: Matched Survey and Medical Record Data

N=151



Results: Continuum of Care Outcome Measures (N=151)

- Number of scheduled visits: median 4 (IQR:2-6)
 - Number of kept visits (median): 3 (IQR:2-5)
 - Number of missed visits (median): 0 (IQR:0-1)
 - Dichotomous missed visits: 41%
- Visit adherence: 82%
- 4- month visit constancy: 67% (2 out of 3 visits)
- Length between visits (median): 74 days (IQR:40-115)
- Last documented CD4 (median): 563 cells/µl
- Last documented VL (mean): 1,845 copies/ml
- Viral load suppression at last VL (VL<200 copies/ml): 90%



Results: Comparison of Care Groups (N=151)

| Care Patterns | HRSA Definition | Self-Report No. (%) | Medical Record No. (%) |
|------------------|--|------------------------|---------------------------|
| In care | At least 2 visits at least 90 days apart over a 12 month period | 109 (72.2) | 105 (69.5) |
| Sporadic Care | Less than 2 visits at least 90 days apart in the last 12 months | 31 (20.5) | 24 (15.9) |
| Out of care | No evidence of a clinic visit in the prior 12 months | 11 (7.3) | 22 (14.6) |



Results: Agreement in Care Status across Data Sources (N=151)

| | | Medical | | |
|----------------|-----|---------------|---------------|-------------|
| | | IC | SC | OOC |
| Self report | IC | 90 (82.6%) | 14 | 5 |
| | SC | 13 | 10 (32.3%) | 8 |
| | OOC | 2 | 0 | 9 (81.8) |



Results: Agreement in Care Status across Data Sources



Kappa =0.2952 Sensitivity: 87.4% Specificity: 41.7%





Comparison of Missed Visits Across Data Sources



Comparison of Care Patterns Across Data Sources



Conclusions

- Highly insured population with good visit adherence and constancy
- Patients' self-perceived care status inconsistent with medical record data
 - Low agreement of care status across two different data sources
 - Patients overestimate their missed visits and gaps in care
 - Many participants perceived themselves as fully engaged regardless of actual care status on continuum
- Additional data collection and analysis needed to further describe care groups
- Patient education regarding meaning of optimal care engagement may assist in more accurate measurement of care continuum



DC D-CFAR ECHPP-2 Engagement in Care Study Team

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Questions

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Limitations and Strengths

- Limitations
 - Potential selection bias and social desirability bias
 - Small numbers of out of care participants
 - Accounting for clinical site differences (e.g., visit schedules, ancillary services)
- Strengths
 - First systematic look at patient perceptions regarding care status
 - Able to validate self-reported data with clinic (and surveillance) data



Recapture Blitz Summary

| | 2013* |
|--|--|
| Number of clients sent to be contacted | 691 |
| Number of clients contacted | 573 (82.9%) |
| Number of clients reengaged | 59 (10.3%) |
| Number of clients found to be in care elsewhere | 121 (21.1%) |
| Number of clients relocated to another jurisdiction | 61 (10.7%) |
| Number of clients deceased | 19 (3.3%) |
| Number of clients unable to re-engage | 46 (8.0%) |
| Number of clients unable to locate | 216 (37.7%) |
| Number of clients with other disposition | 51 (8.9%) |
| Range of contacts needed to reach a final disposition | 1-10 contacts |
| Reasons Not in Care: Difficulties finding out where to go for care Difficulties getting to the appointment- transportation barrier Difficulties leagning appointment, shild appoint | Didn't Want to Disclose Status in Public Client: Labs were Good |

- Difficulties keeping appointment- child care
- Difficulties keeping appointment- unable to miss work • Difficulties making an appointment- inconvenient appointment times
- Difficulties paying for care

- Nothing Wrong
- Something Came Up
- Upset with Referral Process
- Family Issues

Recapture Blitz Summary

| | 2013* |
|---|----------------------|
| Range of contacts needed to reach a final disposition | 1-10 contacts |
| Methods of Contacts ⁺ | |
| Phone Call | 704 contact attempts |
| • Letter | 168 contact attempts |
| • Other [‡] | 79 contact attempts |
| • E-Mail | 35 contact attempts |
| • In-Person | 28 contact attempts |
| Text Message | 2 contact attempts |
| Number of staff hours required | 385 hours |

Types of Staff Required:

- Administrative Staff
- Behavioral Health Counselors
- Case Managers
- Front Desk Staff
- ID Care Associates

- Medical Assistants
- Nurse Case Managers
- Nurses
- Nursing Assistants
- Nutritionists

- Outreach Workers
- Patient Navigators
- Pharmacists
- Physicians
- Quality Improvement Specialists

- *There are 7 providers reporting activities in this cycle.
- ⁺ There are 43 attempts missing a method of contact (n=1,059)

[‡] Includes: Community Health Workers, Medical Chart Review, Facebook, Pharmacy, and the Inmate Locator/ Department of Corrections